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Nursing Role Implications for Family Caregiving

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Abstract

Objective—To describe the clinical, education and research roles of professional nurses caring for family caregivers.

Data Scores—Review of literature and websites on the professional nursing role and family caregivers.

Conclusion—The growing number of family caregivers of cancer patients need education and support. The professional oncology nurse is best suited to assess, teach and support these family caregivers, as well as contribute to the evidence-base of these areas of practice.

Implications for Nursing Practice—Professional nurses caring for oncology patients need to expand their role to include additional support and education of family caregivers.

Keywords

Professional nursing; nursing role; family caregiving

Family caregivers provide a staggering amount of unpaid care in the United States¹, and this care will expand with the increasing number of patients needing this care. Who can prepare and support these caregivers? Do we know the best ways to provide this education and support? The professional role of the oncology registered nurse consists of clinician, educator, counselor, and researcher and includes the education, support and research that address family caregivers' ability to care for their loved ones. Based on the outstanding articles in this issue, this summary addresses the current status of family caregiving for the cancer population, the role of professional nursing in caregiver preparation and support, and the opportunities for nursing research to provide a scientific basis for educating and supporting family caregivers.

Current Status of Family Caregiving

The number of cancer patients continues to increase, with approximately 1,638,910 new cancer patients expected to be diagnosed in 2012². This increase involves both children and adults. However, the adult population is expanding at a more rapid rate due to the increased

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age of the general population, and the resulting increased occurrence (prevalence) of cancer diagnoses (Figure 1)³. Cancer patients are now being diagnosed earlier, treated earlier, and surviving longer. They frequently experience cancer as a chronic disease, with a recurring cycle of treatment, remission, recurrence, and additional treatment, remission, and recurrence, finally resulting in either a disease free survival, or a declining health and resulting death from cancer. (Figure 2)⁴. Such a chronic disease picture illustrates how family caregiving of this population is more commonly not a one time period commitment, but may continue for years with changing needs depending on the phase of care.

Coupled with this picture of increasing family caregiving needs is the continued pressure on acute care settings to discharge patients as early as possible to lower health care costs. This “early” discharge creates a challenge for the family members to give care previously administered by hospital personnel. A third pressure comes from the changes in health care policy regarding hospitalization reimbursement. In order to minimize readmissions for Medicare patients, payment for hospitalization may be reduced if the patient is readmitted within 30 days following discharge⁵. These trends in healthcare point to the importance of preparing family caregivers to manage complex symptoms (e.g. pain, nausea, dyspnea, fatigue, lack of appetite, dehydration), coordinate medication administration, prevent and/or detect infections, support functional rehabilitation, while making accurate judgments to contact health professional when needed. The health professionals traditionally involved with this preparation are professional nurses.

The Role of Professional Nursing in Family Caregiving Preparation and Support

Family caregivers need preparation to meet the demands of their new responsibilities, including physical care as well as psychological, social and spiritual support. This care varies considerably depending on the patient’s cancer diagnosis. For example, patients with hematological cancers treated with hematologic cell transplant are physically vulnerable when discharged. Their immune system is lowered, making them susceptible to potentially lethal infections. Their appetite and ability to eat is decreased and may result in dangerous dehydration, and nutritional failure. Patients’ emotional needs are great, and revolve around the potential for recurrence, readmission, and death. On the other hand patients with early stage prostate cancer may be discharged with fewer physical changes, such as a potential for urinary retention, but with emotional concerns around a lack of continence, erectile dysfunction, and associated changes in social well being. Patients with a late stage lung cancer diagnosis may be treated completely in an ambulatory setting, with management of chemotherapy side effects and an increasing dyspnea presenting challenges for their family caregivers.

The recognition of cancer as a chronic disease, with treatment, remission, and recurrence leading to additional treatment that starts the cycle again occurs in many cancers and has changed the responsibilities of the family caregiver. These responsibilities are characterized by continued patient caregiving needs, that may change and/or expand over the cancer trajectory, as patient remissions and recurrences take place. Maintaining and improving the health care status of the family caregiver has become a part of the support caregivers need.

Studies have demonstrated that family caregivers suffer emotionally and may be susceptible to a variety of medical conditions. For example, high levels of depression occur in family caregivers⁶. Increased risks for stroke and coronary heart disease have been reported in spousal caregivers of cancer patients⁷. Routine health care may be delayed, resulting in missed primary care visits, delayed routine cancer screening, and postponed dental care⁸.

Thus education and support of family caregivers needs to address both how to care for the patient, and how to maintain the caregiver's own health status.

In many clinical settings, professional nurses are already involved in the education and support of family caregiver. Symptom management education may be provided at discharge; and urgent care telephone support line managed by nurses may be available after hours to answer questions confronting caregivers. A multidisciplinary approach is needed to address pain and other symptom management. Referrals can include assistance from the dietitian for patient eating problems, and support from rehabilitation for issues such as fatigue, decreased stamina, and dyspnea. Referrals to social workers may include psychological support as well as how to address legal, financial, and health insurance problems. All these approaches require the professional nurse to coordinate the care needed for the individual family caregiver. Professional role aspects of counselor and educator provide the basis for nursing to take the lead in this coordination.

Nursing Opportunities for Research in Family Caregiving

The research role of the professional nurse includes identifying and applying evidence-based care as well as participating in the conduct of nursing studies. In the area of family caregiving studies have described family caregiving needs, providing evidence for the content of routine caregiver education and support. Studies of various cancer populations describe the usual physical, psychological, social and spiritual needs of patients, including which needs are to be addressed by family caregivers⁹. Education and support for caregivers should include healthy living activities. Thus, the foundation for the content of the education and support for the family caregivers has begun to be described, is disseminated through the nursing literature, and can be used to build the content for Family Caregiver Programs. Additional studies, however, are needed.

Research on the use of the advance practice nurse in delivering the education and support for family caregivers has tested the content to be delivered, and how the advanced practice nurse can tailor that content for individual family caregiver needs¹⁰. Additional research is needed to determine what can be provided by the professional staff nurse and when the advance proactive nurse needs to be involved. Thus we need to answers to questions of Who should do the teaching? Which patient caregivers need standard instruction and support, and which ones need tailored and individual support? Additional questions that need to be addressed include How the caregiver's health can be sustained, what methods can be used for psychological support – individual support, live group support versus support via the telephone or computer networks.

Some of the evidence for excellence clinical education and support for family caregivers is summarized and synthesized in the papers in this issue. Physical care of both adults and pediatric patient caregivers are addressed. Psychological and social support are presented and spiritual support is defined. Communication is key to good caregiver support, as identified by classification of communication patterns, and how to address each. Distance caregiving challenges are most difficult, and approaches that can work are presented.

Conclusion

A vital role for oncology nurses in support of family caregivers is advocacy. It is our hope that nurses can use the excellent articles in this issue of *Seminars in Oncology Nursing* to become strong advocates for improving the quality of care for family caregivers. Nurses can advocate for improved support services, family education and skills preparation and recognition that family caregivers are equal recipients of our care. The NCI funded training course will prepare 400 professionals as advocates for improved family caregiver support

and our hope is that this issue will encourage thousands of additional nurses to also be strong advocates of family caregivers.

In conclusion, the role of the professional nurse in the education and support of family caregivers is clear. The role includes clinician, educator, counselor and researcher. Coordinating caregiver education and support can best be handled by the professional nurse. By embracing these roles, professional nurses are demonstrating how to practice at the full extent of their capabilities Institute of Medicine of the National Academies¹¹.

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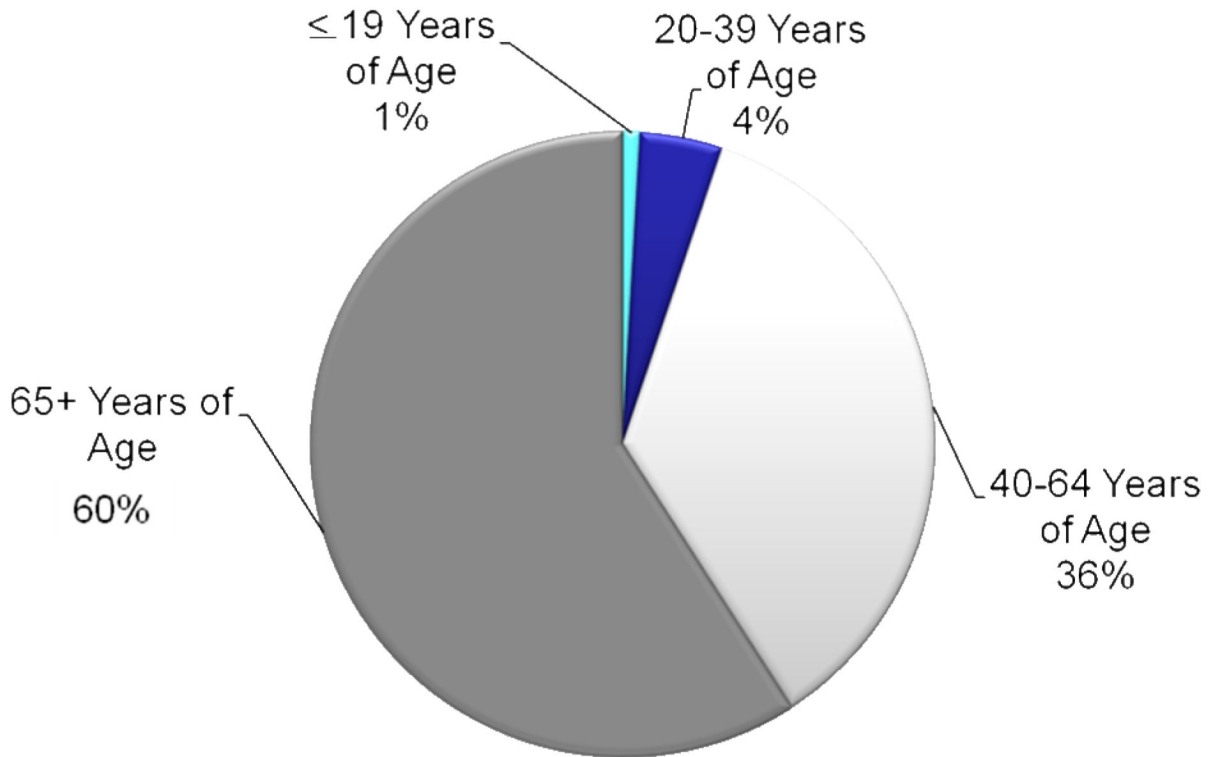
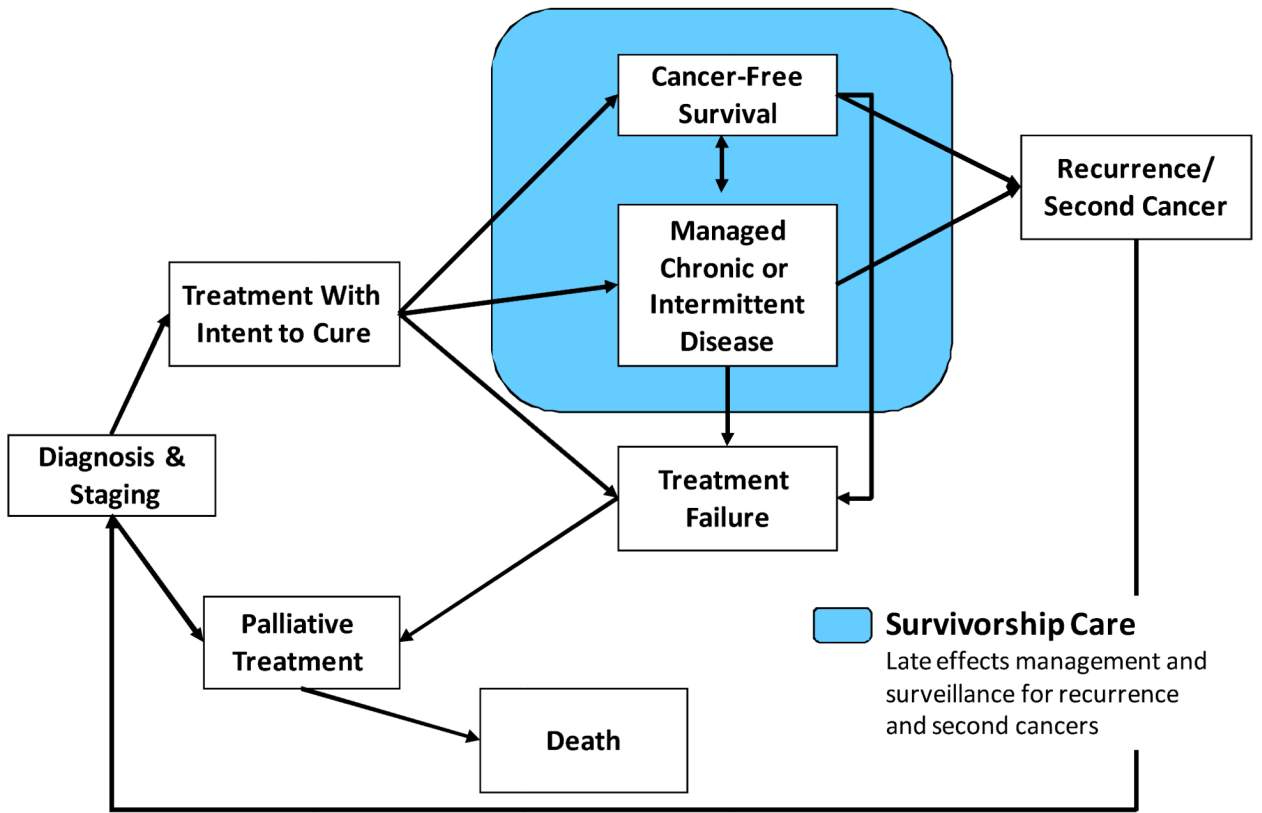


Figure 1. Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2008 by Current Age (Invasive/1st Primary Cases Only, N = 11.9 M survivors)

Data Source: Howlader N, Noone AM, Krapcho M, Neyman N, Aminou R, Waldron W, Altekruse SF, Kosary CL, Ruhl J, Tatalovich Z, Cho H, Mariotto A, Eisner MP, Lewis DR, Chen HS, Feuer EJ, Cronin KA, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2008, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2008/, based on November 2010 SEER data submission, posted to the SEER web site, 2011.



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Figure 2.
Cancer Care Trajectory
Hewitt, M, Greenfield, S, Stovall, E (Eds) From Cancer Patient to Cancer Survivor: Lost in Transition: Institute of Medicine and National Resource Council of the National Academies. Washington DC: The National Academies Press, 2005.